Governor's Commission on Mental Retardation

TRENDS IN COMMUNITY-BASED DAY SERVICES

A Staff Report

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The Commonwealth of Massachusetts

GOVERNOR'S COMMISSION ON MENTAL RETARDATION

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Over the past 30 years, the field of mental retardation has undergone a remarkable transformation in philosophy, organization, and practice. In sharp contrast to the inadequate, almost entirely institutionally-based services of three decades ago, community-based services now encompass a wide range of options including individualized supported living and employment. The vision of quality has been similarly transformed from a "readiness" model that emphasized the need for specialized facilities and training prior to community entry, to a model which promotes community inclusion through active community participation and enhanced self-determination and supports that assit persons to achieve their desired goals. Funding to meet the needs of citizens who have mental retardation remains inadequate. Unlike the budgets for other human service agencies, however, funding for the Massachusetts Department of Mental Retardation (DMR) is at an all time high.

It has been said that in our society, work is the most common, most valued, and most cost-effective way for adults with mental retardation to contribute to society (Lewis, 1991). Across the nation, significant efforts have been made to increase the amount of "real work" for persons with mental retardation. Yet while the policy focus is now on community-based work opportunities, the majority of persons with mental retardation who receive services continue to attend segregated day and sheltered work programs. The situation in Massachusetts mirrors that of the nation: since 1992, the DMR has funded a 36% increase in the number of supported and competitive employment situations, yet more than 61% of all day and work services remain segregated.

The Governor's Commission on Mental Retardation was established through Executive Order in May 1993 for the purpose of monitoring "the quality and effectiveness of the Commonwealth's program of services designed to address a wide range of needs of people with mental retardation." One task in fulfilling this mandate has been to gain understanding of the complexities of the current situation of day and work services provided in Massachusetts. Commission members and staff visited over twenty private providers of day services. Visits were conducted to a variety of day and work services including those that were funded by Medicaid (DMA), DMR and Massachusetts Rehabilitation Commission (MRC). The Commission visited adult day health programs and day habilitation programs, sheltered workshops and supported employment services. [See Appendix for a list of programs visited.] The purpose of the visits was not to evaluate the merits of a specific program but to engage in a constructive dialogue around key issues of day and work services. Specific questions were asked at each visit, but the tone of the meetings was that of an informal conversation.

This report will focus on the findings of the site visits, as well as discussions with experts in the field and a review of the literature. The report is divided into three sections:

- an overview of the history and current trends in day and work services.
- a summary of findings from the field visits including concerns about staffing, quality enhancement, transportation, and obstacles to integrated employment.
- suggestions for future action.

History and Current Trends in Day and Work Services

Historical Background Prior to the 19th century, individuals with disabilities were supported in their own homes or performed tasks for those willing to pay the most for their services. But the industrialization of America and significant waves of immigration resulted in a shift in public ideology about all persons who were perceived as different. No longer could the church and family be depended upon to manage these problems of the community--instead active intervention was necessary for those who were "susceptible to temptation, dissipation, crime, and/or laziness" (Murphy & Rogan, 1995). This intervention took the form of segregation. Persons who were at risk were removed from society for the betterment of themselves and the general population. Philosophically, these separations were supposed to be temporary; in practice, they were more often

permanent. Needy persons were divided into two groups: those who were deemed incapable of caring for themselves were to be cared for at almshouses, and those who could be trained to become useful and employable members of society were to be assigned to workhouses. Concerns about the oppressive, inhumane nature of the almshouses-workhouses system emerged in the late 1800s. This "Progressive Movement" viewed persons with disabilities as helpless individuals who required lifelong, paternal protection and guidance. These three notions: the idea of segregation for the common good, the categorization between those who could and could not work, and the attitude that persons with significant disabilities were helpless all served as a foundation upon which disabilities services were constructed.

It is generally agreed that the first sheltered workshop was founded by Samuel Gridley Howe, Director of what is now called the Perkins School for the Blind in Massachusetts. Significantly, even in this era, Howe was mindful of the risks of segregation. Writing in 1849, he states: "It should be a cardinal principle of the education of the blind to keep ever in view the fact that they are to become members of general society and not a society of blind people..." (cited in Murphy & Rogan, 1995). This notion that a sheltered setting is a first step towards a productive community life was later refined as the "readiness model" whereby sheltered activities were a means to practice skills which could later be used in the community. Sheltered workshops continued to grow throughout the next century, and these facilities were often the *sole* community-based service for persons with disabilities.

*A **sheltered workshop** is "a charitable organization or institution conducted not-for-profit, but for the purpose of carrying out a recognized program of rehabilitation for handicapped workers, and/or providing such individuals with remunerative employment or other occupational rehabilitating activity of an educational or therapeutic nature"* (Federal Register, May 17, 1974, p. 17,509).

Beginning in the 1960's, families began to seek out community-based activities for their children and youth with mental retardation. They developed activity programs through volunteer efforts and private fundraising. With the passage of Chapter 766 in 1972, some of these young people entered the public school system to receive special education services to which they were newly entitled. State funding for adult services gradually increased, and adult day activity

centers and sheltered workshops also emerged as the primary service delivery model. Daily reimbursement for these early programs was astoundingly low with sheltered work funded at $8.50 and day activities $12.50 per day per client.

The advocacy of family members who sought additional services for their loved one was supported by federal legislation. The Rehabilitation Act of 1973 (PL 93-112) mandated the extension of rehabilitation services to persons with severe disabilities and extended constitutional protection of equal employment opportunity and non-discrimination towards persons with disabilities in employment. Research and advocacy focused on convincing society that people with all levels of disabilities could learn if given the opportunity. The enthusiasm and renewed commitment to persons with developmental disabilities has been characterized as an "Era of Optimism" (Bradley, 1994). A new set of theoretical assumptions emerged stating that regardless of the severity of their disabilities, all persons could grow and learn. "This optimism spawned a sense of idealism that made the normalization principle seem not only possible but inevitable" (Bradley, 1994). One of these pioneers was Marc Gold who sponsored training forums which were impassioned demonstrations of the power of effective teaching:

> *Gold's most convincing demonstration came when a young man with obvious severe spasticity and mental retardation (the kind of person professionals usually passed off quickly as 'not feasible for employment') was slowly helped to the stage. The young man, whom Gold had just met a few minutes earlier, sat down at a table in front of a 15-compartment tray containing the sorted parts of a Bendix 70 bicycle brake. Gold positioned himself in a chair to the left of the man and slightly behind him. Then with a little talking, Marc reached forward, took an axle from the first compartment, and step by step added parts from each of the other bins until he held a fully assembled bicycle brake. With a confident 'Lookie there' he sent the brake assembly spinning around the axle.*
>
> *Round two. With Gold's hands over the man's hands, all eyes focusing on the bicycle parts, they assembled a brake together.*
>
> *Round three. The man was gently encouraged to assemble a brake himself. Then Gold's hands were less*

> *involved, and when a part fitted on the axle wrong, Gold quietly said, 'Try another way.' The man did so, and the process continued until the assembly was complete.*
>
> *Round four. The young man successfully put a brake together himself, spun on the axle, and broke into a broad grin.* (Perske, in McLoughlin, Garner & Callahan, p. *vii*.)

The combination of research, training, and advocacy did much to convince society that people of all levels of disability could learn if given the opportunity.

The 1980s saw a national shift toward integrated employment for persons with significant disabilities. The Education of the Handicapped Amendments of 1983 (PL 98-199) addressed the lack of transitional assistance for persons leaving special education. The shift in the economy from manufacturing to services as well as the refinement of service technology related to employment supported this effort. The benefits of supported

Supported employment *is..."paid work in a variety of settings; particularly regular work sites, especially designed for a handicapped individual for whom competitive employment at or above minimum wage is unlikely; and (ii) who, because of the disability, needs intensive, on-going support to perform in a work setting* (Federal Register, September 25, 1984, Section 102, [11],[F].

employment were cost efficiency, increased wages, increased social inclusion, and the diminution of stigmatization. Many sheltered workshops added a supported employment component. Initial pilot programs documented impressive results, and four program models emerged.

- **individual placement** where an employment specialist or job coach helps develop a job, trains the worker, and then fades from the site when the worker is ready for independence. This continues to be the most highly utilized model of supported employment, however, persons with significant disabilities comprise only a small percentage of those who work in this model. Individual placements can be cost effective, when compared to sheltered settings if the job coaching can be time limited.
- **enclave model** is a group supported employment site where a permanent, on-site staff member supervises workers with disabilities. This model is cost effective especially for persons who require long-term supervision. Initially, this model was viewed as one which promotes social inclusion, but recent studies have shown that persons in an enclave have limited social contacts with other employees.
- **mobile work crews** are small, mobile businesses in which groups of persons with disabilities travel to do cleaning, janitorial, groundskeeping, and light assembly tasks. Staff generally remain with the crew. Social inclusion is limited by this model because workers are segregated and not permanent members of a business.
- **entrepreneurial model** is similar to the enclave and mobile crew. Workers go to a fixed site with persons with disabilities. Some models integrate disabled and non-disabled workers at the same location.

Goals for these new programs initially focused almost exclusively on achieving higher earnings through increased wages and longer hours of paid work. As the field of supported employment developed, quality of life issues came to the forefromt especially those which valued community integration and enhanced social roles. " Financial criteria cannot be the sole measure of the value of employment because most workers derive benefits from working other than the earnings reported on a wages and tax statement" (McLoughlin et al 1994).

Supported employment opportunities have been the most visible and rapidly growing method of assisting persons with mental retardation to be included in society. While few other initiatives experienced such remarkable growth, yet even in the midst of rapid expansion, opportunities remained scarce, and the number of sheltered placements continued to grow. Nationally, in 1989, only 5-6% of persons with mental retardation were in supported employment programs (Lakin and Hill, 1989). Perhaps even more significantly, less than 10% of adult day programs have downsized or reallocated resources, and less than 5% have eliminated segregated programs (Wehman and Kregel, 1994). Thus supported employment added an additional component to segregated services rather than a becoming a tool which reduced the reliance on segregated settings. Concerns about the funding of dual systems and about the increases in segregated settings led the Association for Persons with Severe Handicaps (TASH) to call for dramatic changes:

> *TASH calls for rapid and immediate development of individualized and integrated employment for all people with severe disabilities and the rapid and permanent replacement of segregated activity centers and sheltered workshops* (November 1989).

The rapid expansion of supported employment in the 1980s led many to believe that similar increases would be a product of the 1990s. Federal legislation again supported the expansion of community-based employment through the Rehabilitation Act of 1992 and removed the "employability" standard for eligibility thus making the presumption now that all were employable. But instead of the rapid and permanent replacement of segregated activity centers as called for by organizations like TASH in 1989, few advances have been made in this decade. As Mank notes in his article entitled "get title": " On balance, the national supported employment initiative appears to be an underachiever: an initiative that has raised expectations, with high quality in its selective demonstrations and innovations but failing in scope and quality of implementation" (1994).

The Training and Research Institute based at Children's Hospital in Boston undertook a national survey of integrated employment (McGaughey, Kiernan, McNally, and Gilmore, 1993). With 41 state MR/DD agencies (80%) providing data, they found a substantial (5%) increase in overall numbers of persons served in integrated employment settings between 1989 and 1991. This was accompanied by a continued emphasis on segregated settings: 44% of all those served attended

sheltered work settings and 37% attended non-work day programs. Furthermore, many persons with less significant disabilities remained in segregated settings: 48% of all those in day programs and 68% of all those in sheltered work had mild or moderate mental retardation.

New participants to day programs were more likely to be served in competitive and supported employment, and those waiting for services were seeking twice the number of supported employment slots as those waiting for segregated settings.

One reason why segregated day services continue to dominate is the utilization of federal Medicaid dollars. 63% of all day service dollars come from state MR/DD funds, however the next largest percentage--25%--come from federal Medicaid grants in the form of Title XIX, Home and Community-Based Waiver (HCBS) and Title XX funds. These funds go to non-work services such as day habilitation programs. The Home and Community-Based (HCBS) waiver funds can be used for pre-vocational services and supported employment for those who currently live in ICFs-MR or who have previously been institutionalized. Although supported employment may be funded through the HCB waiver, in FY'90, the preponderance of spending was devoted to non-work programs: 84% of HCB waiver funds went to day habilitation services, 11% went to pre-vocational work activity centers, and only 5% went to supported employment.

Higher than anticipated costs of supported employment have also limited expansion of the services. The early supported employment programs started with the notion that a job coach--a trained staff person who would accompany the worker to the paid placement--would initially provide intensive training and then fade involvement. This model of time limited support was viewed as being very cost effective in comparison to a sheltered work setting with permanent staff supervision. However, the difficulties with fading the job coach led to more long-term staff supports which increased the cost of care.

In an effort to reduce costs by reducing dependence on paid staff and to increase integration, the role of natural supports has also been reviewed. By involving the co-workers, employers and others directly supporting the individual and using the job coach primarily as a resource to the natural supports, the long-term placement of staff on-site is avoided. The newest thinking around supported employment focuses attention on self- determination. A truly customer driven model in which workers and their families have control over what types of services they buy is predicted to blend the model of on-site paid job supports with unpaid supports from co-workers. "Recapturing the initiative can only happen if we form new alliances with people with disabilities, invest in employers and the community, put greater control of resources in the hand of people with disabilities, and turn away permanently from the segregation of the current system" (Mank, p.170).

Trends in Massachusetts

Expansion in Supported Employment Massachusetts has doubled its spending for supported employment since 1992. This contribution has resulted in significant gains in integrated empoyment opportunities--a 78% increase in less than five years. This expansion has been a critical issue for the leadership of the DMR especially in the past two years during which time three of the agency's twelve management goals were directed at enhancing integrated employment In each of the three areas, the results have surpassed the goal by between 22 and 120% (See Figure 2). The re-orientation of day services to integrated employment is impressive especially given the absence of federal reimbursement for supported employment. As noted earlier, only those who current live in an ICF-MR or have a history of institutionalization are able to have their supported employment billed to HCBS waiver. Since Massachusetts has no community based ICFs-MR, supported employment is entirely state funded. It is signifcant that funds have been re-directed to supported employment during this time because the Commonwealth has allocated 19% less funding in inflation adjusted terms for MR services during this same time period (Braddock & Hemp, 1996).

Although Massachusetts has made impressive gains in its supported employment opportunities, it continues to lag behind its New England neighbors including Vermont, New Hampshire, and Connecticut. Per Capita spending on supported Employment is current $3.41 in Massachusetts. Vermont, New Hampshire and Connecticut all spend over $5.00 in 1996 (Braddock & Hemp, 1996).

Rapid expansion in day services All types of day servcies have expanded during the past 4 years. Both Medicaid funding for day habilitation programs and DMR day programs have undergone a raid expansion. All services-- both work and non-work oriented--have increased by a total of 36 %. (see figure 1) Today, over 75% of all day and work services take place in segregated settings, with a net expansion of supported and competitive placements increasing less than 5% in the past four years. (See figure 2)

Changes in contract codes. In an effort to simplify the contracting process, Massachusetts DMR has compressed all day services four contract codes: education and training services for people with extensive and pervasive needs, a small group of DMR funded day habilitation slots *, employment supports which includes both sheltered and integrated settings, and alternative day supports for persons with fewer support needs but do not wish to pursue work. (see figure 3 for definitions)

* As noted earlier in the paper, DMA (Medicaid) usually funds the day habilitation service, unless that person lives in a facility which is supposed to provide 24 hour services such as a nursing home. For those persons, DMR pays for Day Habilitation slot often on a part-time basis.

DMR FY'96 MANAGEMENT GOALS (#1-3)
Figure 1

GOALS	Region I		Region II		Region III		Region V		Region VI		TOTAL	
	goal	actual	goal	actual	goal	actual	goal	actual	goal	actual	goal	actual
1. Integrated Employment for people in sheltered workshops (provider paid, may include enclaves and work crews).	35	77	110	156	45	119	83	246	85	192	358	790
2. Employer paid supported employment for people in sheltered workshops.	31	48	76	122	46	65	90	93	65	65	308	393
3. Divert sheltered workshop placements for new consumers to integrated employment.	8	11	18	18	18	44	16	15	30	22	90	110

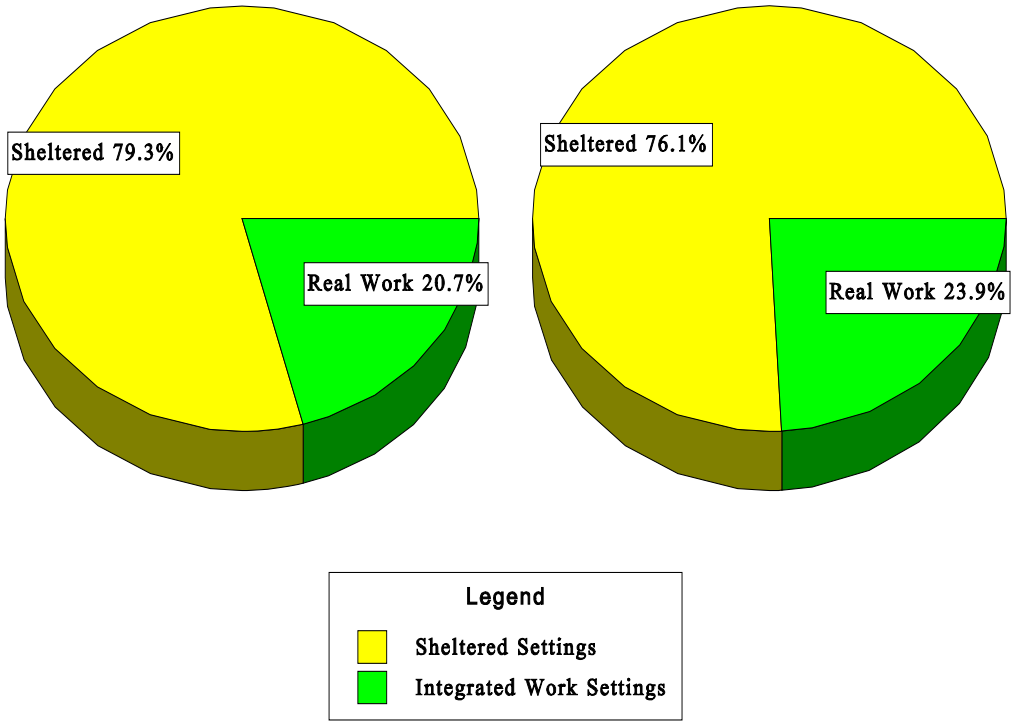
Massachusetts
Persons Receiving Services
funded by DMA and DMR
Figure 2

Program Model	1992	1996	% increase
Day Habilitation (DMA Funded)	1050	2007	91%
Day Activity/Sheltered Work	6774	8245	22%
Supported Employment	1403	2504	78%
Competitive Employment	637	721	13%
Totals	9864	13477	36%

Data Sources, DMR FY'96 Annual Report, 1992 day hab figures are from Braddock et al, 1995 ; 1996 figures are from oral communication with the Division of Medical Assistance.

MA Trends in Employment 1992 & 1996

Figure 3



FY'96 DMR Day and Employment Services Information

Figure 3

Program Code	Description	Capacity	# of Contract Budgets	FY'96
3163	Education and Training Services Day activities typically for consumers with extensive and pervasive support needs. Support can assist in learning self-help, academic, language, social, and vocational skills with an overarching goal for the consumer to reach their optimal potential.	2190.40	210	$26,955,739.72
3164	Day Habilitation This Medicaid funded service provides short-term, medically oriented therapy to multiply handicapped individuals. The goal is the stabilization of individuals to enable them to participate in further training. Some service components include basic training in activities of daily living and nursing services, occupational, physical, recreational, speech and hearing therapies, as needed. The program must meet Title XIX standards and policies.	206.00	30	$1,573,557.03
3168	Employment Supports Employment supports for consumers of all abilities. Supports assist individuals to prepare for and experience gainful employment, and may include sheltered employment, work crews, enclaves, provider-owned businesses, volunteer work, provider-paid employment, with the overarching goal of quality jobs for consumers.	4694.30	249	$41,739,339.61

3171	Alternate Day Support Daily supports for consumers who are not interested in education or job training or employment. Supports are designed based on the preferences of each individual and are avocational in nature. Community resources are used extensively to provide for socially integrated experiences.	277.20	50	$3,169,389.58
TOTAL:		**7,367.90**	**539**	**$73,438,025.94**

Themes from the Site Visits

Staff and members of the Governor's Commission on Mental Retardation met with twenty providers of day and work services. At times, the meetings were with the executive director alone, but more typically the meetings were held with a group of senior and middle managers and often with direct service staff and users of the service. The Commission found that most providers were eager to talk about both the struggles and satisfaction of their work. Although these organizations offer a diverse range of options, Commission members and staff found a surprising amount of consensus regarding the accomplishments and on-going concerns among the groups. This section of the report will review the four most prevalent themes including: direct care staffing, quality assurance mechanisms, transportation, and obstacles to integrated employment.

Direct Service staff--salaries, turnover and training Without doubt, the single biggest concern among providers was the *low salaries* for direct service workers. During the course of the interviews the Commission met dedicated young staff persons who revealed that their full-time job in day services was often only one of many. One gentleman carried a full college course load while working at one full-time and two part-time jobs. This earned him about $25,000 annually and a room in a group residence as a live-in staff person. Working so many hours created challenges for these individuals to attend trainings and participate in evening meetings. More significantly, very few of the young persons intended to make human services a career. As one executive director, who pays her entry level workers $19,000 (with the state average at $ 16,500), told the Commission: "If you want quality service--committed people who service, who are well-educated and concerned about the quality of life in addition to client safety, something must be done about salaries!"

Mitchell and Braddock, in their significant study of wages and staff turnover (1992), note that the low pay of direct service workers has been a particularly longstanding problem. They cite an example from 1912 in which "the notoriously insufficient pay" was viewed as the major reason why staff turnover was running at 70% in New York Institutions (p.290). Mitchell and Braddock cite reasons for low direct service wages. They include: gender bias, in that women always earn less than men in a field dominated by women, low social value to the job of "servicetaking" work, and the charitable origins which are the historic base for these types of supports and have always paid near poverty wages. The study also noted the dramatic difference between public and private wages with state workers

earning an average of 46% more than those employed by private agencies. This substantial difference was due primarily to the step increases available to long-term employees in most state systems. Virtually none of the providers visited rewarded longevity of service, and the absence of such increases was exemplified in the case of one woman who as a college graduate with a degree in special education and a person who had worked in the field for nearly twenty years, she earned $20,000 per year. This woman commented that she and her husband feel that they make a "charitable contribution of $15,000 per year" to persons with mental retardation--the difference between her actual earnings and what she would make as a school teacher.

Surprisingly, the level of direct service *turnover* varied significantly from agency to agency even when salary and geographical location were taken into account. Instead, type of service seemed to have a greater impact on turnover. Smaller, individualized agencies which provided only integrated employment had little trouble keeping staff. People who worked for these organizations frequently noted that they had found their "niche" and planned to remain in their current position for a long time. One small program which has no "facility" for day services also has essentially no turnover, with many persons remaining in their current jobs for five or more years. Recent studies have noted high levels of satisfaction among supported employment specialists (Parent, 1994, Test, Hinson, Solar and Keul, 1993), and the turnover rates at these integrated employment services further support these data. Mitchell and Braddock noted that the national turnover rate ranged from 31-71% annually. The providers met with did not experience such high levels of turnover in their day services, however, many commented that their residential contracts--with the abundance of evening and weekend hours--often hit turnover rates of 50% or more.

The Commission staff and members were pleasantly surprised to encounter a significant commitment to staff *training*. The leadership of each agency recognized the importance of such training and appeared to have the internal capacity to provide at least the mandatory trainings which include First Aid and CPR, safety training medication administration, Human Rights and ISP training. Many providers used a competency-based system whereby new employees have to complete all the mandatory trainings during the first three months of employment. Most used a combination of on-site training by the individual supervisor as well as classroom training. Some providers pooled their training dollars to maximize their benefit. Others made a substantial commitment to on-going skill development through mandatory annual training requirements. Although the mandatory training

seemed to be well managed, providers expressed dismay about the high cost of providing the 16 hour medication administration training. Some felt that this "unfunded mandate" exhausted the training budget and focused staff training almost entirely on health/safety measures, rather than on developing the skills needed to support self- determination, choice making, and inclusion. For providers who had high turnover rates, there was concern about the ceaseless aspect of training. Given the intensive initial investment in staff training, the benefits of an experienced staff were never realized because the worker left the agency soon after the training was completed.

Other providers noted with concern that the "paradigm shift" from services to individualized supports would dramatically increase staff responsibility and independence and thus increase the need for intensive training. One executive director noted that "People working more independently in smaller settings will need a whole new array of skills, and they won't get the benefit of working side-by-side with more experienced workers as role models." Many nationally recognized leaders concur that training will have to be significantly intensified if the individualized model is to be fully implemented. [Add a piece on HSRI training project] In 1993, the Boston-based Institute for Community Inclusion conducted a national survey of supported employment specialists and their managers. Their survey noted that 92% of respondents ranked further training as an "overwhelming interest." Nearly one half of program managers and employment specialists indicated that they had received no training in supported employment practices from their agency. Topics chief interest included: working with the business community and job development especially for persons with more significant challenges, involving consumers in individual service design and delivery, and developing program goals that support community employment and sufficient funding.

Quality enhancement--the dual systems of CARF and QUEST

Tremendous amounts of time and funding have been devoted to the assessment and monitoring of MR services. This is particularly true in states like Massachusetts which have been subject to lengthy consent decrees. Like most other states, Massachusetts had devoted much of its quality assurance

*The **DMR QUEST survey** is divided into six major quality of life areas which reflect those aspects of living that would be considered quality in the lives of all people. They are:*

- *Respect and Dignity*
- *Individual Control*
- *Community Membership*
- *Relationships*
- *Personal Growth and Accomplishments*
- *Personal Well-Being.*

activities to measuring the "inputs" and "outputs" of a particular program--that is, DMR licensed its providers based on the safety of their physical facilities, the number and training of their staff, and their capacity to provide services to a certain number of persons. The DMR recognized that the specific focus on health, safety, rights, and ISP implementation was an inadequate means of "buying" quality, and it abandoned the old licensing system in 1994. In its place was a certification process based on the Quality Enhancement Survey Tool (QUEST). All DMR-funded day services must now be certified by the QUEST survey. Because Day Habilitation funding comes from Medicaid (not DMR), these programs do not undergo a QUEST. Instead, the Day Habilitation provider must pay for a quality assurance survey from one of two national evaluation processes: CARF--the Rehabilitation Accreditation Commission and the Accreditation Council on Service for People with Disabilities. Site visits are also conducted by the Division of Medical Assistance (DMA--Medicaid). Currently, no day habilitation provider uses the Accreditation Council survey which, like the DMR QUEST, is an outcomes-based measure. The CARF evaluation has recently been revised to better address the need for providers to "manage outcomes", it remains a traditional measurement of inputs and outputs--that is on the delivery of services rather than the results of those services. It continues to survey of a program rather than a sampling of individual achievement or satisfaction.

Nearly all day habilitation providers also provide DMR-funded day services. In fact, day hab sites are often located in close proximity to sheltered work settings. Thus a single agency often has its day services assessed by two very different types of tools--and apparently with quite different results. Several providers the Commission met with held the highest level of CARF accreditation for their day hab settings, but their DMR-funded programs were only certified conditionally by QUEST.

Attitudes toward CARF and QUEST Providers of day habilitation services are uniformly satisfied with the CARF system. They find it objective, timely, and consistent. The values of QUEST also received universal praise, but providers expressed concerns about the implementation of the program especially during the initial certification process. Early on in the site visits, the Commission encountered complaints about the training of the QUEST surveyors, and several providers suggested that the QUEST pilot should have been continued for a full year before it was implemented.

Several providers noted that the QUEST survey was more applicable to

residential services than day services, and they felt that separate tools for each type of service would be valuable. Commission staff met with June Rowe, Director of Survey and Certification to review these concerns. She reported that a separate tool had been considered in the design of QUEST, however, it was decided that a "whole-life" tool better integrated the values of the DMR Mission statement. In addition, the QUEST tool has been refined so that certain sections (such as the part about making friends) can be "not rated" by the QUEST surveyors of day programs. If this aspect of the survey is rated during a survey, it is to provide commendation. Several providers of both residential and day services noted that the day services received less evaluation and comment in the reports and oral feedback. June Rowe also agreed that the residential component did receive more attention in the initial survey but that a better balance had been achieved in the re-certification process. Because so few agencies have been re-certified, it is hard for this to be assessed, but in one report reviewed, a better balance was achieved.

Several providers also suggested that there be distinct categories for agencies who are under conditional certification due to "inputs" measures such as safety and human rights measures and those who are beginners in the "journey to full inclusion" and thus receive conditional certification in community membership or individual control.

Transportation Not surprisingly, concerns about transportation to and from work and day programs were multiple--in fact for several providers, transportation was the number one "headache issue."

Transportation as the key to job development In September 1995, the Governor's Commission on Mental Retardation sponsored a public hearing on transportation. During the hearing, Pamela Sampson from Alternatives Unlimited noted that "Transportation is one of the most challenging aspects of getting people jobs in the community because public transportation is not readily available... employment opportunities are tied to people's transportation rather than the needs of the employee or the employer." This concern captures the fundamental necessity of having adequate transportation in order to make "real work" possible. All providers who had successful individualized employment services also had the capacity to provide individualized transportation. This was generally done by employment specialists who used their own cars or, in urban areas, via public transportation. During the site visits, one provider noted the necessity of re-thinking the notion of "providing" transportation. He had recently re-convened a summer "school-to-

work" training program in which no transportation was provided due to budget cuts. Families who enrolled their adolescent children in this training agreed to provide the transportation. Each family did so, often through flexible, "natural" solutions such as car-pooling with neighbors. This provider noted that "we had never considered making such a demand on families, but now we have to begin thinking about it."

Concerns about transportation provided by others Increasingly over the years, the Regional Transportation Authorities (RTAs) have coordinated transportation for citizens who have mental retardation. Some providers viewed this as a positive, cost effective strategy. One executive director noted that some "regular" bus routes had been changed to better accommodate his clients' needs. Vans leased by the local Council on Aging were now used to provide transportation for his clients which he felt was a good use of resources. Another provider, who held DMR-funded day, residential, and transportation contracts, expressed concern about the RTAs. This provider experienced difficulty with drivers not providing door to door transportation in bad weather. She gave an example of one client who was dropped off at the end of his street to walk to his residence when he was not to be left alone in the community. Another example involved a person with mobility challenges who had to walk across an icy parking lot instead of being dropped off in front of the work place.

Several providers mentioned that the transportation companies do not adequately train their drivers or monitors. This was especially troublesome for those providers who supported people with significant behavioral challenges. Incident reports were not filed, and clients came into day programs upset following difficult van rides. One provider noted that the RTA had now taken on the management of transportation of very challenging clients. This is a "specialty service" which requires training for the drivers and monitors on those vehicles. This training was not provided. Further evidence of this lack of training is also found in the Seaside Education Associates, Inc. Report on Transportation (November, 1995). While this report, commissioned by the DMR Office on Quality Enhancement, noted that both consumers and families are highly satisfied with transportation in general, it also noted that 25% of drivers did not receive the training that was mandated by the Department's contract. 35% of monitors assigned to vehicles to promote client safety had not received the necessary training.

For site-based day programs, staff spoke frequently about their frustration with inconsistency in drop off and pick up times. This was especially taxing for direct service workers who often needed to leave on time for school or a second job. Senior staff spoke of their difficulties in providing the contractually managed staff ratios when their programs were functionally staffed for as much as 90 minutes longer each day due to late transportation. In addition, because staff usually do not receive overtime for staying late but are given compensatory time off later in the week, transportation delays often made significant impacts on regular program time as well. One provider was diligent in providing activities for the very behaviorally challenged clients who were waiting for transportation, but this was accomplished at the expense of staff meetings and training time.

Concerns when transportation is provided by the provider Over the past few years, the DMR has increasingly contracted for transportation directly with the agency who provides the day service. Many recognize the quality advantages of this system, especially because staff who are trained and well known to the client also provide the transportation. However, taking on this project has been a monumental task for some agencies. Leadership in the provider organizations were especially worried about the potential rise in workers' comp rates if their direct service workers became classified as drivers. One provider noted that the current workers' comp rate was between $2-4 per $100 of insurance. This rate would balloon to between $9-10 per $100 if her workers were classified as drivers. In addition, it was noted that when direct service workers take on the responsibility of transporting clients, they risk a dramatic rise in the cost of their auto insurance, because they are using the car for work-related activities.

Obstacles to Integrated Employment Significantly, providers were united in their opinion that integrated employment is the best option for most persons with disabilities. Regardless of whether a provider had most of its employees on-site or in integrated employment settings, the value of integrated employment was universally affirmed. Providers discussed a myriad of obstacles to creating more integrated, "real work" placements. These concerns focused on funding restrictions and overall costs, family and community resistance.

Funding restrictions By definition, Medicaid-funded day-habilitation programs are site-based, non-work oriented programs. Not only must a program participant be unpaid for his or her activities, but also the focus of these programs must be on therapy and skill development rather than work. With over 2000

participants in the Commonwealth attending these programs, this limitation has a profound impact. In addition, because of significant DMR waiting lists, day habilitation slots are often the only available option for day services. Some providers have been able to work around this Medicaid restriction by providing unpaid opportunities (i.e., "selling" craft items through requested donation, and other volunteer work). Others have worked with DMR to provide a few hours per day or week of DMR-funded support which allows for paid work. Most of this paid work is in a workshop, but there are examples of persons with significant disabilities working in individualized, off-site placements for 2-3 hours shifts and then returning to the day hab setting for therapy and group work.

While there was a consensus among providers that integrated employment was a valued, realistic choice for their clients, no provider felt that supported employment could be significantly expanded without a major infusion of funding. When the concept of supported employment was initially touted, the program developers assumed that individualized job coaching would be time limited, and thus a cost-effective alternative to the sheltered work setting. The reliance on long-term, on-site paid support on the job dramatically expands the cost of services. The providers estimated that it would cost at least twice as much to provide long-term on-site job coaching in 1:2 ratio as it would to provide a sheltered setting. One provider exclaimed: "Give me $15,000 per year [per person], and I'll get everyone out!" Individualized job development that relies on natural supports in the workplace have been found to be effective, but most providers felt that their clients' needs were too intense to make use of unpaid supports.

"Day custody" Providers often expressed concern that they were mandated to provide two very different kinds of services. One was to provide a type of "day custody," consisting of safe supervision for 30 hours per week (five six hour days); the other was to promote job training and job placement. These disparate activities were often in conflict with one another. Entry level jobs were usually part time and often included evening and weekend hours. If the person receiving support could not stay home alone either with family or in the group residence, it was often impossible to work outside the typical 9am-3pm workday. Several providers noted that if the person lived in a group residence, they did not even attempt to develop a job outside of the 9am-3pm schedule, because there was never enough flexibility in residential staffing patterns to permit this.

Family concerns about security Some providers found that family members

were very reluctant to have their loved ones outside of the sheltered setting. Families were concerned about the loss of the social network of the sheltered workshop; they worried that their family members would be teased or traumatized in an inclusive setting. Other family members were more open to the notion of "real work" but wanted assurances that their loved ones not earn enough money to jeopardize their SSI or MassHealth benefit. Other providers found little resistance to integrated employment. One noted that only one out of his 64 clients was "held back" because of his mother's concern about the loss of the SSI check. Another noted that there was a need for the provider to "hold the family's hand" through this process, but as long as support was given, family reluctance was not insurmountable. Other providers who offered only integrated employment services encountered no resistance at all because "real work" was the only service option.

Community Obstacles Several providers suggested that *economic downturns* hit their consumers the hardest. One provider in Southeastern Massachusetts noted that at one point all his clients were out working in integrated settings, but due to several major economic cutbacks in his region, 25% were now working in the sheltered setting. Many providers said that employers were willing to hire persons with disabilities, but that they were dependent on long-term job coaching, because employers insisted on having human service persons present permanently. Several providers also noted that businesses much preferred to sub-contract work to the workshop rather than have disabled workers come to the business to do the work. Nor was the Americans with Disabilities Act (ADA) viewed as helpful. One provider noted that he had found that the ADA hurt his consumers, recounting an experience with a major employer who said, "If I hire them, I'll never be able to fire them."

Staff resistance Most agencies provided both sheltered and integrated services, and some found staff reluctance a significant issue. One provider noted that middle managers had the most difficult time seeing the possibility of real change, while direct service workers could see the potential of their clients. Another provider noted that she had spent too much time "bringing people along" rather than stating that integrated employment was the new organizational standard and letting staff leave if they were unhappy with the new direction.

Communication of expectations Three providers noted that DMR had difficulty responding positively to significant movements towards integration. One noted that he now had half of his clients in the community, reducing his facility

needs by 50% with no recognition by DMR of his achievement. Another noted with chagrin that his clients who set up a coffee shop in a rest home and were paid a stipend out of provider funds were not considered employed by the DMR even though their social inclusion and active work had dramatically improved.

One provider who was actively seeking to increase integrated employment found that DMR communicated mixed messages to vocational providers. On the one hand, Central Office DMR was clear about expanding integrated employment offerings while the local and regional offices persisted in referring clients to the sheltered settings. She noted that she would never be able to "close the shop" unless she was given a real mandate to cut off admissions to the site based program.

Findings

Day services remain segregated. Both the literature and the Commission's site visits repeatedly demonstrate that if the proper supports are provided, real community work is possible for most persons with mental retardation, including those with severe disabilities. While the success of the initial supported employment programs has been widely communicated, their positive outcomes have changed the vision of quality more than practice. Even in Massachusetts, where DMR funding has expanded supported and competitive employment by over 75% in five years, most citizens who receive day services remain in segregated settings. The chief reasons for this are:

- Federal regulations direct the use of Medicaid dollars to non-work settings.

- The costs of long-term individualized job coaching are prohibitive. In the current system, the day service is implicitly required to provide two disparate activities: to provide a safe, supervised environment for 30 hours per week and individualized job training in a community setting. Current reimbursement for these dual activities is inadequate.

- Supported Employment has been viewed as an additional service to day programming rather than as an alternative to traditional models. In effect, supported employment becomes one aspect of the continuum of service which goes from the most restrictive setting of the day habilitation center to the integrated job placement. In a national survey from 1993, less than 5% of agencies were planning to eliminate their site-based day programs, thus perpetuating the need to run facilities as well as provide employment. No provider with whom the Commission met is currently planning to close its facility.

Day habilitation centers are accredited by a system that places less emphasis on inclusion than the QUEST does. The day habilitation centers, which are often located within DMR-funded sheltered work programs, undergo quality assurance evaluations which are significantly different than those of the DMR-funded programs. This dual system is confusing for families and individuals seeking admission to a program because it obscures and limits the ability to promote community inclusion.

Providers are struggling with a myriad of priorities and often function at or near "crisis mode." This situation limits an organization's ability to create effective long-term plans. Particular difficulties include:

- Low entry level salaries limit a provider's ability to have an experienced, well trained staff. As programs become more individualized, this training will be even more crucial.

- Transportation delays create on-going stress which impacts the quality of programming and impedes training time.

Action Steps:

- **Highlight low cost (i.e. same cost) ways to promote community-integrated employment.** The goal of community-based employment is universally embraced throughout Massachusetts. This is heartening news, but the implementation of these values within the current budget structure is clearly an unmet challenge. Some persons with intensive needs will require long-term job assistance, but if those with few needs are able to work with less supervision and if savings can be realized through some reduction in the use of facilities, more of these long-term placements will become a reality. Some agencies have demonstrated that increases in integrated employment without the high costs of continuous job coaching are possible. These practices need to be analyzed and shared with all providers.
- **Evaluate day hab programs using outcomes-based tools such as the Accreditation Council or the DMR QUEST.** It is clear that day habilitation programs will continue to play a significant role in the continuum of day services, continuing the practice of "non-work" oriented programs. What is unacceptable is while citizens who receive DMR-funded services benefit from a quality assurance system which promote values of community inclusion, over 2000 others who receive Medicaid-funded day habilitation do not. Using the QUEST or the Accreditation Council will not help persons with significant disabilities gain employment, but the funds and staffing can promote a great deal of social inclusion.

- **Conduct a thorough examination of the possiblitiy of moving the**

oversight of day habilitation programs from Medicaid to DMR

- ***Continue the commitment to raise base direct service salaries.*** Staff recruitment and retention is of grave concern to providers. Throughout the site visits, the Commission met with staff dedicated to doing quality work, yet the conditions under which they worked hampered their capacity to become long-term contributors to the field of mental retardation. The best and the brightest direct service workers often make choices to leave the field upon completion of their education due to insufficient wages. Providers were unanimous in their assertion that low direct service salaries were the single biggest obstacle in quality of service.

Appendix

Sites Visited

Region I
New England Business Associates
FOR

Region II
Alternatives Unlimited
Barry Price
Riverside
TILL
Horace Mann Educational Associates

Region III
Bass River
CMarc
Shore Collaborative

Region V
BAMSI
Community Connections
Nemasket Group
Road to Responsibility

Region VI
Boston Business Associates -- get full name
Charles River Arc
Greater Waltham ARC
Kelleher Center-- get full name

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